

End-of-Life Decision Making: History, Tools, and Cultural Competency

By Geoff Bernhardt
Attorney at Law
Law Offices of Geoff Bernhardt P.C.
5603 SW Hood Avenue
Portland, Oregon 97239-3714
(503) 548-4000
geoff@elderlawpdx.com
www.elderlawpdx.com

I. Cultural Competency: Major Themes.

A. End-of-Life Decision Making in the Dominant Culture.

1. Patient Autonomy
2. Complete Information about Diagnosis, Prognosis, and Treatment Options.
3. Use of Advance Directives.
4. Ability to Choose or Refuse Life-Prolonging Medical Care.

B. Other Cultures, Other Themes.

1. Mistrust of the Medical System.
2. Importance of Religious Beliefs.
3. Degrees of Truth-Telling about Diagnosis and Prognosis, and the Concept of “Informed Refusal”.
4. Family Involvement in Decision Making.
5. Family Responsibility for Patient Care.

II. Negotiating Cross-Cultural Issues at End of Life.

A. Culture and Medical Care.

Culture fundamentally shapes the way people make meaning out of illness, suffering, and dying. It influences how they make health care decisions and use medical services at the end of life.

Failure to take culture seriously means we elevate our own values and fail to understand the value systems held by those of different backgrounds.

Misperceptions caused by lack of cultural sensitivity can lead to poor interaction with clients, patients, and their families at critical junctures as life comes to a close.

For example, if a family from a different culture believes that knowing the truth about his or her diagnosis and prognosis is harmful to the patient, a physician, care

provider, or attorney who persists in telling them the direct “truth” may be perceived as cruel, uncaring, and ignorant. The result is mistrust and anger, and may result in the end of the professional relationship or the removal of the patient from the care setting.

Assuming someone would not want to be told about her diagnosis because she is from a particular cultural background is stereotyping. Insisting that she must be told is a form of cultural imperialism. The challenge is to navigate between these poles.

B. Patient Autonomy: The Dominant Culture, the Dominant Mode.

In the Euro-American model, patient autonomy is the primary focus of decision making at the end of life. Patient autonomy emphasizes the rights of patients to be informed about their condition, its possible treatments, and their ability to choose or refuse life-prolonging medical care. Advance directives for health care are used to insure that patients’ wishes concerning end-of life care are enforced even when they are no longer able to speak for themselves. Patients and families from other cultures may not share these values and concerns.

C. African-Americans and End-of Life Care.

When working with African-American clients/patients, consider three factors: (1) lack of trust in the medical and legal systems (2) desire for full communication about diagnosis, prognosis, and treatment options and (3) the influence of religion in making end-of-life decisions.

1. Lack of Trust in the Medical System: A Response to Inequities.

African-Americans are less likely than white patients to trust the motivations of physicians who discuss end-of-life care with them. More likely to feel that they would be treated differently and receive lower-quality treatment if they completed an advance directive for health care. African-Americans are more likely to believe that economic motivations are behind physicians’ decisions to remove life support.

African-American patients are more likely to want aggressive medical care at the end of life. One study: African-Americans were 3 times more likely than white patients to want aggressive treatment at end of life. Another showed that 37% of African-Americans wanted cpr when terminally ill, as opposed to only 16% of white patients

2. Desire for Truth Telling in Diagnosis and Prognosis.

African-American patients generally want to be informed about the diagnosis and prognosis of a terminal illness, and want to make decisions about medical care. One study showed that African-American patients are among those most likely to want to discuss preferences for CPR, but not to have done so.

Suggestions: (1) avoid use of medical/legal jargon and (2) check with the patient/client to verify that he or she has understood the communication and has had all of his or her questions answered.

3. Influence of Religion.

In one study, African-Americans revealed their beliefs that only God has knowledge about – and power over – life and death, and that physicians cannot have access to this type of knowledge. “The doctor doesn’t know everything. God might come into it . . . He can do more for us than the doctor can. Only God can tell you how long you have to live – the doctor can’t do that.” Many would continue all measures until the end because it “is wrong” to stop and miracles are always possible. Patients would feel guilty about stopping life support. A physician’s statement that the situation is hopeless may not be adequate: only God knows for sure.

There is also the view of suffering as redemptive. It is to be endured, rather than avoided. Foregoing life support in order to avoid pain and suffering might be seen as failing a test of faith.

D. End-of-Life Decision Making for Asian-Americans.

When working with Asian-American patients/clients, understand that end-of-life decisions may be influenced by three important considerations: (1) patients/clients may not want complete information about their diagnosis, prognosis, and treatment options; (2) end of life treatment decisions may be made by the whole family, not just the individual patient/client; and (3) direct patient care may be considered the responsibility of the children and services like hospice may be resisted.

1. Truth Telling and “Informed Refusal.”

Informed consent is a major tenet of US health care. However, truth telling about diagnosis and the prognosis of potentially fatal illnesses like cancer is not the norm in much of the world. In Italy, France, Eastern Europe, most of Asia, Central and South America, and the Middle East, physicians and patients often feel that withholding medical information is more humane and ethical. The reason given for withholding information about diagnosis or prognosis is that the truth may be cruel and is potentially harmful to the patient.

One study found that Chinese-American families oppose truth telling about a potentially fatal illness because the patient would lose hope and suffer unnecessary physical and emotional distress.

Another study: only 35% of Korean-American subjects believed that patients should be told of a terminal prognosis. One Korean American in the study kept his wife’s cancer diagnosis a secret from her. “If she knew, she would not be able to live longer because of the fear.”

The issue of a patient's desire to hear "the truth" about his or her diagnosis and prognosis is complex, in that people who don't want the blunt truth may wish to know the truth through other, indirect means. The purpose of indirect communication is to preserve "face," that is, never to put the person one is talking to into a position of embarrassment or loss of honor by directly posing potentially sensitive questions. In these cultures, indirect or nonverbal communication may be preferable, because the ambiguity saves face and allows for the possibility of hope.

As an example of an indirect strategy, a physician can make an offer of information to the patient, allowing the patient the option of "informed refusal." The physician establishes with the patient who should receive all medical information and make decisions regarding the patient's care. If the patient designates that someone else be given this responsibility, this constitutes the patient's informed refusal to be included in the discussions or decision making.

A second example would involve the use of a "hypothetical case." This respects the need for indirect discussion, and implicitly invites further questions. Watch for indirect questions from the family. Be sensitive to gauge the degree of information sought. Being too direct may frighten the patient/family, and they may not pursue the inquiry.

2. Family Involvement in Decision Making.

The dominant culture in the US values the rights of individual patients to make decisions about their care at the end of life. In other cultures, decision making may be seen primarily as a duty of the family, whose responsibility it is to protect the dying patient from the burden of making difficult choices about medical care.

Studies show that Hispanic-American, Korean-American, Chinese-American, and Japanese-Americans strongly believe that the family should be the primary decision maker.

Family involvement in end-of-life decision making occurs in all cultures. The question is: do family members support the patient by encouraging him or her to make choices, or do they express their love by taking on the decision-making burden themselves?

3. Hospice Care – Family Responsibility.

Ethnic minority populations comprise over 25% of the US population, but represent only 17% of patients enrolled in hospice. Very few of these are Asian-Americans. "Filial piety," or the expectation that children will care for their parents without question in gratitude for their parents' care and sacrifices, may account for this. Hospice, which constitutes accepting care from outsiders, may be seen as dishonoring the parents. Broaching the topic of hospice care with Asian-Americans challenges the value

of filial piety and must be done very carefully. Asian-American families will use hospice services, but usually in the home and usually with considerable oversight and control. The issue of “face” will also be present for Chinese, Japanese, and Korean groups. How well they care for their parents is open to community scrutiny and judgment, and it would reflect poorly on the parenting abilities of the parents and on the extended family if the children do not fulfill their obligations.

E. End-of-Life Decision Making for Mexican Americans.

When advising or treating Mexican-American patients/clients, consider (1) the influence of religion, (2) the importance of family decision making; (3) the fact that the patient may not wish to know the blunt truth about diagnosis and prognosis; and (4) the possibility of miscommunication with physicians and attorneys.

1. Religion.

Most Mexican-Americans are Catholic; their religious beliefs oppose anything that hastens death. There is always the hope that the patient may get better, so to stop life support may cause the Mexican-American family great feelings of guilt. There is the belief that enduring sickness is a sign of strength.

2. Family Involvement.

When a patient is terminally ill, the family is involved in all aspects of decision making. The well-being of the family is valued over that of individual members. Traditionally the father or husband is the head of the household and should make or agree with all decisions. The wife’s input is highly influential, but may not be highly visible.

3. Truth-Telling about Diagnosis, Prognosis, and Treatment Options.

In one study, 52% of Mexican American patients stated that patients should not be told the truth about a terminal prognosis. There is the belief that the truth about a terminal prognosis should not be told because it hastens death.

4. Possibility of Miscommunication.

Understand that Mexican-American patients may consider directly contradicting a physician to be rude or disrespectful. A physician may believe that that a patient and the patient’s family are in agreement with the physician’s plan of action when in fact they are strongly opposed to it. There is a strong tendency toward paternalism, and physicians may be expected to make life support decisions for their patients.

F. End-of-Life Decision Making Among Muslim Americans.

Consider (1) the influence of religion; (2) the degree to which truth-telling in diagnosis and prognosis are desired; (3) the extent of reliance upon the physician to make important decisions and (4) that the family is expected to be demanding in end-of-life care situations.

1. Influence of Religion.

Life and death are viewed as controlled by God. The body is a gift from God, and it is a moral duty to seek medical help when needed. Because only God can decide when someone will die and all are mandated to seek medical attention, life support is viewed as an obligation, not an option. Stopping life support is thought to be “playing God,” although starting life support is not. Opposition to withholding life support holds true even if a patient is in considerable pain. Long-term suffering presents an opportunity to show courage and faith in God.

2. Truth-Telling in Diagnosis and Prognosis.

Initiating a discussion of the issues of life support might anger a patient or family. Telling a patient that there is no hope is viewed as possibly hastening death and is considered inappropriate and insensitive. Given the U.S.’s informed consent laws, some form of dialogue about the terminal nature of a patient’s disease is usually necessary. Approach the subject carefully and slowly, first engaging in small talk – it may be rude to go directly to the point.

3. Reliance Upon the Physician to Make Important Decisions.

The concept of options and patient autonomy may be foreign. Patients are not used to being asked to make choices and may delay doing so. The health care team may become frustrated with patients because they cannot make up their minds when in fact the patient is expecting the physician to make the decisions regarding their care.

4. Family Expected to be Demanding of Health Care Professionals.

In some Middle Eastern countries, the family is expected to be demanding. This shows concern for the family member. The family may expect to remain in the hospital with their loved one and insist upon a wide range of medical care that care staff may view as futile. Not to do so could indicate that they do not care about their family member. Care staff may become frustrated with this demanding behavior, and to understand the reasons behind it may alleviate some of the friction it causes.

G. End-of-Life Decision Making Among Korean-Americans.

Consider the importance of (1) religious beliefs; (2) filial piety (3) paternalism in end-of-life decision making.

1. Religion.

Most Korean-Americans are religious. Many Korean-Americans interpret stopping life support as interfering with God's will, although starting such measures is not. Placing value on longevity is part of a strong Taoist influence among Korean Americans.

2. Filial Piety.

Filial piety, or loyalty to one's parents, is very important. Children owe their lives to their parents. They are responsible for the parents and must preserve their parents' lives at all cost. To agree to stop life support may dishonor the family member in the eyes of relatives or the community. How people's actions are viewed by others is important; issues of "face" may be involved.

3. Paternalism in Decision Making.

Traditional concept of obedience to the male head of the family. Tradition dictates that a patient should die at home.

H. End-of-Life Decision Making among Orthodox and Non-Orthodox Jews.

Understand that there may be great differences in attitudes toward end-of life care between Orthodox and non-Orthodox Jews.

1. Orthodox Jews.

Traditional Orthodox Jewish teachings are firmly in favor of continuing life support. An Orthodox patient may become upset at a health care team for even bringing up the subject of stopping life-support measures. Life is sacred and to be preserved whenever possible. The sanctity of life is more important than its quality. It is mandatory to maintain one's health and to seek health care when needed. Doctors cannot make a judgment about another person's quality of life because life may have meaning under all conditions, even when the suffering is immense. Patients must seek life-sustaining measures, and physicians must provide them.

2. Non-Orthodox Jews.

The views held by Orthodox Jews concerning life-sustaining treatment are not necessarily held by non-Orthodox Jews. Generally more likely to subscribe to the values of patient autonomy and full disclosure held by the dominant culture.

I. **End-of-Life Decision Making Among Gays and Lesbians.**

The experience of living with HIV/AIDS or knowing someone living with HIV/AIDS, and the legal status of gay men and lesbians and their partners, affects the way gays and lesbians view end-of-life decision making.

1. Preference for Palliative Care. Gay men and lesbians generally support a palliative approach to end-of-life care. 86% preferred palliative care vs. only 14% supporting care designed to extend life. In the general population, 70% report a preference for palliative care.

2. Support for Physician-Assisted Suicide. An overwhelming 92% of lesbians and gay men endorsed legalization of physician-assisted suicide in at least some situations, vs. 65% of the general population. 83% of gay male respondents could imagine requested physician-assisted suicide for themselves, vs. 50% of the general population.

3. Importance of Advance Directives for Health Care. 90% of gay men and lesbians were aware of advance directives for health care; approximately 42% had completed them, vs. only 28% of the general population. The uncertain legal standing of partners of gay men and lesbians facing end-of-life issues makes the completion of an advance directive for health care a critical part of their planning.

4. Desire to Discuss End-of-Life Care Issues with Physicians. While 73% of gay men and lesbians report a desire to discuss end-of-life care issues with their physician, 79% report that they had not had this discussion.

5. Other Cultural Issues Should be Considered. Gay men and lesbians come from a variety of cultural and religious backgrounds. These backgrounds influence how they approach end-of-life decisions and should be considered. For example, while gay men and lesbians are generally strong supporters of legalization of physician-assisted suicide in at least some cases, gay men from an African-American cultural background are significantly less likely than white or Hispanic gay men to support physician-assisted suicide.

III. **Summary of Cross-Cultural Issues in End-of-Life Decision Making.**

a. Physicians and attorneys should use knowledge about particular cultural beliefs, values and practices to respectfully recognize a person's identity and to assess the degree to which the individual or family might adhere to their cultural background.

b. Understand the concept of "informed refusal" of diagnostic or prognostic information.

c. Understand that in some cultures it is traditional to delegate end-of-life decision-making powers to the family or to specific older relative.

d. Understand that some cultures have a desire for life-sustaining treatment even if medical providers consider the care to be futile.

c. Institutions – the Bar, doctors, hospitals, care facilities, home care and hospice agencies, should take responsibility for facilitating culturally competent advice and care.

IV. Health Care Decision Making Tools.

The recent Terri Schiavo case illustrates the importance of specifying one's wishes about end-of-life health care. Ms. Schiavo lived in Florida and experienced health problems that left her comatose and on a feeding tube. Her husband believed she would not have wanted her life prolonged through the use of a feeding tube. Other members of her family believed that she would have wanted the feeding tube. The husband and other family were involved in a long, highly-publicized court battle over whether Ms. Schiavo would continue to be fed through a tube. Unfortunately, Ms. Schiavo never signed a health care directive specifying her wishes about end-of-life care. If she had, her wishes would have been honored, and her family would not have had to fight over the type of care she received.

In Oregon, there are three documents commonly used to specify one's wishes about health care decisions in the event you are not able to communicate those wishes: a living will, a durable power of attorney for health care, and an advance directive for health care. Two other ways, a POLST form and guardianship enable others to make these health care decisions. All of these methods are described below.

a. Living Will. Also called a Directive to Physicians, a living will is a document stating that a person does not want life-sustaining treatment if two doctors certify that he or she is in a terminal condition, and that life-sustaining treatment will only postpone the moment of death. This document was widely used in the late 1980's and early 1990's. The main problem with a living will was that it did not appoint someone to review medical records and communicate wishes about end-of-life care to medical staff.

b. Durable Power of Attorney for Health Care. The Durable Power of Attorney for Health Care was designed to supplement the living will. This document allowed a person to appoint an agent to communicate with health care providers and make decisions about end-of-life care. The main problem with this document is that it expires seven years after it is signed. A secondary problem is that the form was ambiguous, requiring the person to write the word "yes" to indicate that he or she did not want life support or tube feeding.

c. Advance Directive for Health Care. The Advance Directive for Health Care was authorized by the Oregon legislature in 1993. This form combines the best features of the living will and the power of attorney for health care. It allows an individual to appoint a health care representative to make decisions about health care in the event he or she is unable to do so. It also allows a person to give instructions to a health care

representative so he or she will have a clear understanding of the ill person's wishes. The form does not automatically expire after a certain period of time, and can be good for the person's entire life. It also allows a person to make additional comments about end-of-life decisions. An advance directive for health care is the best way to ensure that an individual's wishes about health care would be respected if faced with a life-threatening illness or injury.

d. POLST – Physician's Orders for Life-Sustaining Treatment. This is a document on bright pink paper that can be placed in a person's medical chart. It sets forth physician's orders concerning certain types of end-of-life care. It must be signed by the doctor. Some people obtain completed POLST forms and post them on the refrigerator so they can be seen by paramedics in the event of a medical emergency.

e. Guardianship. A guardianship is a court order allowing one person to make health care and placement decisions for an incapacitated person. If a person has not appointed someone to make health care decisions (for example, by signing an advance directive for health care), it may be necessary to seek the appointment of a guardian. People who suffer from dementia, Alzheimer's Disease, or other illnesses affecting the ability to make important decisions often need the assistance of a guardian to make placement decisions.

A guardianship is expensive. It is far better to rely upon the advance directive for health care to appoint someone to make health care decisions for an incapacitated person. Even if an advance directive for health care has been signed, a guardianship will sometimes be necessary to make placement decisions.

Geoff Bernhardt, J.D.
University of Oregon School of Law, 1992

Geoff has been helping individuals and families address the legal and financial consequences of aging for 14 years. He has been a guest speaker regarding estate planning and elder law for the Multnomah Bar Association, the Oregon Gerontological Association, the Alzheimer's Association, the Oregon State Bar, the Oregon Chapter of the National Multiple Sclerosis Society, the Office of the Long-Term Care Ombudsman and the Oregon Law Institute. Additionally, the Oregon State Bar sought Geoff's assistance in writing a book on Elder Law for Oregon attorneys. Geoff is a prior recipient of the Multnomah County Legal Aid Senior Law Project Outstanding Volunteer Award. Geoff's firm, the Law Offices of Geoff Bernhardt P.C., specializes in elder law, estate planning, probate, guardianships and conservatorships. He is on the Board of Directors of the Oregon Gerontological Association; the Program Committee and the Long-Term Care Committee of the Oregon Chapter of the National Multiple Sclerosis Society; and the Executive Committee of the Elder Law Section of the Oregon State Bar.

Sources

Blackball et. al. *Ethnicity and attitudes towards life sustaining technology*. Social Science and Medicine 48 (1999).

Kagawa-Singer et. al. *Negotiating Cross-Cultural Issues at the End of Life*. Journal of the American Medical Association Vol. 286, No. 23 (2001).

Classing, J. *The effect of values and culture on life-support decisions*. The Western Journal of Medicine Vol. 157 (1992).

Carlos et. al. *The Influence of Ethnicity and Race on Attitudes toward Advance Directives, Life-Prolonging Treatments, and Euthanasia*. The Journal of Clinical Ethics Vol. 4 No. 2 (1993)

Stein, et. al. *Attitudes on End-of-Life Care and Advance Care Planning in the Lesbian and Gay Community*. The Journal of Palliative Medicine Vol. 4 No. 2, (2001).

OREGON HEALTH CARE INSTRUCTIONS – PART C OF ADVANCE DIRECTIVE

Here are my desires about my health care if my doctor and another knowledgeable doctor confirm that I am in a medical condition described below:

1. **Close to Death.** If I am close to death and life support would only postpone the moment of my death:

A. INITIAL ONE:

I want to receive tube feeding.

I want tube feeding only as my physician recommends.

I DO NOT WANT tube feeding.

B. INITIAL ONE:

I want any other life support that may apply.

I want life support only as my physician recommends.

I want NO life support.

2. **Permanently Unconscious.** If I am unconscious and it is very unlikely that I will ever become conscious again:

A. INITIAL ONE:

I want to receive tube feeding.

I want tube feeding only as my physician recommends.

I DO NOT WANT tube feeding.

B. INITIAL ONE:

I want any other life support that may apply.

I want life support only as my physician recommends.

I want NO life support.

3. **Advanced Progressive Illness.** If I have a progressive illness that will be fatal and is in an advanced stage, and I am consistently and permanently unable to communicate by any means, swallow food and water safely, care for myself and recognize my family and other people, and it is very unlikely that my condition will substantially improve:

A. INITIAL ONE:

I want to receive tube feeding.

_____ I want tube feeding only as my physician recommends.

_____ I DO NOT WANT tube feeding.

B. INITIAL ONE:

_____ I want any other life support that may apply.

_____ I want life support only as my physician recommends.

_____ I want NO life support.

4. Extraordinary Suffering. If life support would not help my medical condition and would make me suffer permanent and severe pain:

A. INITIAL ONE:

_____ I want to receive tube feeding.

_____ I want tube feeding only as my physician recommends.

_____ I DO NOT WANT tube feeding.

B. INITIAL ONE:

_____ I want any other life support that may apply.

_____ I want life support only as my physician recommends.

_____ I want NO life support.

5. General Instruction. INITIAL IF THIS APPLIES:

_____ I do not want my life to be prolonged by life support. I also do not want tube feeding as life support. I want my doctors to allow me to die naturally if my doctor and another knowledgeable doctor confirm I am in any of the medical conditions listed in Items 1 to 4 above.

6. Additional Conditions or Instructions. _____

_____ (Insert description of what you want done.)